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Executive Summary

Participatory action research (PAR), involves inclusive research approaches where people who would typically be seen as the subjects of research become full or partial participants in the research process. PAR is intended to promote social change for marginalized groups, such as people with intellectual disabilities (ID), through the removal of barriers that prevent participation and allowing people to exert control over all, or part of the research process and outcomes. Project UNIFY of Special Olympics International (SOI) partnered with Special Olympics Maryland (SOMD) and public school students to pilot youth-led research methods that model our values, including respect, dignity, and self-determination. Broadly, SOI was interested in understanding what it means to students with intellectual disabilities to feel included in their schools and communities.

SOI employed PAR methods that engaged young people with and without intellectual disabilities as co-investigators. SOI implemented the investigation for and with—not just about—young people. Students with and without ID from three schools in Maryland worked as teams to explore a social issue of importance in their school. In addition to formulating a research question, students served as researchers through the following activities: creating data collection instruments; collecting and interpreting data; presenting findings; and making recommendations for changes in schools and communities. Students attended a training session where teams brainstormed potential research questions. From this session, the teams approached several critical social issues on their campuses including the role of social media, the impact of stereotyping, diversity and acceptance, and the impact of Unified Sports. The research teams provided reports of the results as well as recommendations for future action in each respective area at a full group session in April 2013.

Background

THE ROLE OF PARTICIPATORY ACTION RESEARCH

Participatory action research (PAR), involves inclusive research approaches where people who would typically be seen as the subjects of research become full or partial participants in the research process. Depending on the level of inclusivity, these people may be the instigators of ideas, create the research design, collect and/or analyze data, author reports, and work to disseminate the results. PAR is intended to promote social change for marginalized groups, such as people with intellectual disabilities, through the removal of barriers that prevent participation and allowing people to exert control over all, or part of the research process and outcomes.

There are varying levels in which a community can be involved in the research process. Depending on the level of this involvement, power within the research framework will vary. At a minimum, PAR involving people with ID should be guided by the following principles:

- The research question, problem or issue must be one that is owned (though not necessarily initiated) by people with intellectual disabilities.

4 Ibid.
5 Ibid.
- It should further the interests of disabled people: non-disabled researchers should be on the side of people with intellectual disabilities.
- It should be collaborative. People with intellectual disabilities should be involved in the process of doing the research.
- People with intellectual disabilities should be able to exert some control over the process and outcomes.
- The research question, process and reports must be accessible to people with intellectual disabilities.

This approach can be taken one step further (often referred to as ‘emancipatory research’) by increasing the element of empowerment within the research design. Zarb (1992) argues that involving people with ID in a meaningful way is only the first step in creating a research framework that is the most beneficial to people with ID. He believes that research will not be emancipatory until people with ID are empowered to fully control the research process by deciding who should be involved, to what degree, and what should be studied.

Others also emphasize that in order for PAR to be truly community-based, emancipatory, empowering, etc. community members must be given leadership roles in all phases of the research process, including initiating the process and taking part in analysis. The National Institute for Environmental Health Sciences (NIEHS) emphasizes principles for emancipatory research that align with Paulo Freire’s principles of dialogical (two-way) action. In addition to leadership roles at all levels, these principles encourage co-learning between the community participants and researchers, a commitment to using culturally appropriate strategies, allowing communities to self-define who they are, assure that projects are community driven, and disseminate results in meaningful ways.

**IMPLICATIONS OF USING PARTICIPATORY METHODS**

Montoya and Kent (2011) emphasize that traditional research methodologies dichotomize researchers and those being researched leaving little room for flexibility, and that participatory methods are more ethical, improve construct development, improve construct and intervention validity, and improve knowledge accountability. Additionally, Johnson (2009) and Garcia-Iriarte et al. (2009) found that using participatory methods enabled some people with ID to become stronger self-advocates, and that these projects empowered people with ID to work in groups to create their own projects to make change happen. The positive findings from these studies and several others show promise for the continued engagement of people with ID in research.

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6 Ibid.
10 Ibid.
Inclusion throughout the research process has been found to increase active participation of people with ID in projects. Garcia-Iriarte et al. found that many people involved in the research group from the beginning actively participated in meetings when given the opportunity to share ideas or give input. Group members were also able to engage through logistical means such as setting up rooms for focus groups and keeping time during meetings. Active participation at the early stages of the project is necessary for the group to take control of the research and influence outcomes. 

These findings illustrate that meaningful inclusion can empower people with ID to be actively involved throughout the research process, and outcomes from participation can be seen on at least three levels: the individual psycho-social level; life skills level, emphasizing the acquisition of competencies; and the institutional level as participation can empower people with ID to look further into issues that are important to this population and potentially fight for policy changes at various levels of government or within the community. Tufte and Mefalopulos explain that, “By engaging all relevant stakeholders, participatory communication becomes a tool that helps alleviate poverty, mitigates social exclusion, and ensures priorities and objectives are agreed to and refined by a wider base of constituencies” (2009, p. 18).

Project Description

SCHOOL SELECTION

To carry out the project, SOI partnered with Special Olympics Maryland (SOMD), a lead partner in Project UNIFY, and with Roy McConkey who served as an external consultant on implementing participatory methods. With guidance from SOMD leaders, four high schools in Maryland were selected as pilot sites. Schools were selected based on their current level of engagement with Project UNIFY, expressed interest in research, and demonstrated commitment to cultivating leadership among students with and without disabilities. Due to schedule conflicts, only three of the four selected schools carried out student-led projects; however, one school had enough interest from students to form two research teams. School selection took place in June and July 2012 and the three participating schools were Maurice J. McDonough High, Walkersville High, and Severna Park High. Students and faculty advisors were paid a small stipend for participating in the project.

RESEARCH ACTION TEAMS

SOMD helped identify schools in which a strong faculty advisor was present as this was a key component to the success of the project. In addition to having a faculty advisor for students, each of the schools built a Research Action Team, with 8-10 student investigators per team. Faculty advisors guided the recruitment process and recruited students with and without intellectual disabilities through Unified Sports and other components of Project Unify. SOI provided guidance for student recruitment in order to help faculty advisors identify students that would be a good fit for the project. See Appendix A for a sample of the guidance provided to faculty advisors. Student recruitment and team formation took place in August 2012. All students and/or guardians provided consent to participate in the project. See Appendix D for a copy of the consent form given to all student investigators.

In December 2012, SOI and SOMD hosted a training session for all of the schools at the SOMD headquarters where each team was tasked to plan and implement a one-year research study that built knowledge about a question they deemed important. During this full-day session students received information on research methods including the basic steps in conducting a research project, obtaining

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13 Ibid.
Special Olympics 

consent from participants, collecting and analyzing data, and sharing results. Several brainstorming sessions and group activities throughout the day gave students the opportunity to interact with each other and share ideas for potential projects. All of the students and faculty advisors received a binder with information from the training session and tip-sheets for reference throughout the course of the project. See Appendix B for a sample of the information provided to students and faculty advisors. The reference binder was one of several ways students were supported throughout the project. In addition to written materials, teams received support from their respective faculty advisor as well as from SOI staff via bi-weekly check-in meetings at each school. All of the students and faculty advisors came together for a wrap-up session in April 2013 to present their findings and ask questions of the other teams.

Student Projects
From the initial training session, the teams approached several critical social issues on their campuses including the role of social media, the impact of stereotyping, diversity and acceptance, and the impact of Unified Sports. The research teams provided reports of the results as well as recommendations for future action in each respective area. Each of the final products can be found in Appendix C.

MAURICE J. MCDONOUGH HIGH SCHOOL
“How does stereotyping effect the school environment?”
Maurice J. McDonough High School is located in Pomfret, MD in the Charles County Public Schools District. The school serves approximately 1,226 students in grades 9-12. The research team at McDonough High consisted of nine students, one male student and eight female students. The students were in grades 10-12, and four of the students were enrolled in special education classes. The faculty advisor selected two student leaders who then recruited seven additional students to participate in the project. Most of the students also participate in the Best Buddies program on campus and learned about the project through that group and through their faculty advisor who serves as an advisor to the Best Buddies program.

The research team at McDonough High looked at the impact of stereotyping on bullying in their school. The group brainstormed potential research questions at the training session provided by SOI in December 2012. Over the course of the school year, the group developed a survey with eight quantitative questions to understand attitudes about race, disability, and social class among students at the school. The research team distributed the survey to classes that incorporated a variety of students based on grade level and academic performance (i.e. Advanced Placement, Honors, Special Education, etc.). Through this process the group received 452 survey responses. To collect qualitative information the research team selected students to participate in a focus group. Focus group participants volunteered to be part of the group and agreed to have the session video recorded. The research team created a Powerpoint presentation to share with faculty and students at McDonough High (Appendix C).

Key Findings:

- 57% of students reported that stereotyping is a problem at their school
- 43% of students reported having been excluded; conversely, 93% of students reported spending time with someone of another race outside of school
- 74% claimed to have stood up for someone with a disability, and 65% felt that McDonough High is welcoming to students with disabilities

http://www2.ccboe.com/schoolscenters/viewschool.cfm?id=55
WALKERSVILLE HIGH SCHOOL
“How does social media affect the students at Walkersville High?”
Walkersville High School is located in Walkersville, MD in the Frederick County Public County Schools District. The school serves approximately 1,124 students in grades 9-12, of which, 9.4% are enrolled in Special Education services. The research team at Walkersville High consisted of ten students, five male students and five female students. The students were in grades 9-12, and five of the students were enrolled in special education classes. The faculty advisor selected two student leaders who then recruited eight additional students to participate in the project. Most of the students also participate in the Special Olympics Unified Sports program on campus and learned about the project through that group and through the faculty advisor who serves as a coach for Unified Sports.

The research team at Walkersville High looked at the role of social media at their school. The group brainstormed potential research questions at the training session provided by SOI in December 2012. Over the course of the school year, the group developed a survey with 15 open-ended and closed-response questions to understand the ways in which social media has impacted students at Walkersville High. In order to reach the most students, the research team distributed the surveys to every English class on campus. Team members made a presentation in each classroom to explain the purpose of the survey and answer any questions from students. The team received 225 survey responses, which they analyzed and presented through Prezi (Appendix C).

Key Findings:

- If used in the right way, social media can have a positive effect on students as 59% of students have used a social network to start a friendship.
- There are negative effects as well, 27% of students claimed to have stayed home from school because of something they read on a social media site and 25% have been bullied by others on a social media site.
- Most students surveyed felt that social media has had both a positive and negative influence on student life.

SEVERNA PARK HIGH SCHOOL
“How can Severna Park High become a community more accepting of diversity?”
“What is the impact of Unified Sports at Severna Park High?”
Severna Park High School is located in Severna Park, MD in the Anne Arundel County Public Schools District. The school serves approximately 1,857 students in grades 9-12 and is affiliated with the Hannah More School for students with a primary identification of emotional disability, autism, learning disabilities, other health impairment or multiple disabilities. The research teams at Severna Park High consisted of two groups of 9 students each. One group partnered with students at the Hannah More School, a program for students with Autism Spectrum Disorders, and the second group worked with students enrolled in traditional special education classes. Ten male students and eight female students participated in the project. The students were in grades 10-12, and eight of the students were enrolled in special education classes or the Hannah More School. The faculty advisor selected two student leaders who then recruited the additional students to participate in the project. Most of the students

16 http://apps.fcps.org/sp.cfm?i=67
http://www.hannahmore.org/about.html
also participate in the Special Olympics Unified Sports program on campus and learned about the project through that group and the faculty advisor who serves as a coach for Unified Sports.

The first research team looked at diversity in the school and assessed student attitudes about diversity on campus. The group brainstormed potential research questions at the training session provided by SOI in December 2012. Over the course of the school year, the group developed a six question survey to understand attitudes about diversity and behavior among students at the school. The research team distributed the survey to classes that incorporated a variety of students based on grade level and academic performance (i.e. Advanced Placement, Honors, Special Education, etc.). Through this process the group received 80 survey responses. To collect qualitative information the research team selected students to participate in qualitative interviews. Interview participants volunteered to have the interview video recorded and used in a video presentation of the results (Appendix C).

**Key Findings:**

- Most students recognized race and religion as a type of diversity, but no students recognized disability as a form of diversity
- 30% of students who reported having been excluded from an activity cited ability as the reason for being excluded
- In order to become a more accepting community, it is important to reach out to those who may not otherwise reach out themselves.

The second research team looked at the impact of Unified Sports at Severna Park High. The group brainstormed potential research questions at the training session provided by SOI in December 2012. Over the course of the school year, the group created a qualitative interview format for collecting data. The team conducted interviews with students, faculty, and alumni to understand the evolution of Unified Sports over time. The research team interviewed students of all grades and ability levels, and interview participants volunteered to have the interview video recorded and used in a video presentation of the results (Appendix C).

**Key Findings:**

- Unified Sports has had a positive impact on students and teachers at Severna Park High School
- Students with disabilities felt that they were able to be accepted into the sports culture within the school because of Unified Sports
- Students with and without disabilities wished there were more Unified Sports opportunities within the school
Student Feedback
Following the completion of the project, SOI administered a survey to collect feedback from the students on various elements of the project process. Students were asked about the participatory and inclusive nature of their research groups, how well the project helped students learn about research methods, and development of leadership skills.

Key Findings:
- **30 students participated in the survey from each of the three schools**
- **94% felt that teamwork was encouraged within their team, work assignments were distributed fairly, and that the ideas and opinions of everyone in the group were heard**
- **88% said that they made friends with someone they did not know before working on this project**
- **All of the students that responded said they would take action because of what they learned from their project.**

“I thought that the PAR Project was an incredible experience in both learning how to perform a research project and learning to interact with special ed. students. I thoroughly enjoyed working with my friends from unified sports on this project and I would love to improve research studies and techniques through performing this project again. I thank everyone who worked on this project for their help and participation in improving the life and research skills of everyone on the team.”

“It would be nice perhaps to do a follow up project based on our findings, as well as sharing the information we gained with fellow students.”

“The only comment I have is that we should have more schools involved to show that more people are participating in this project. Having only 3 schools was good, but having about 10 schools will bring more voices and different opinions and make this project even better.”
Best Practices and Discussion

Students were also asked for feedback on ways future iterations of the project could be improved, as well as to give an overall grade for several of the key components of the process. From this feedback, conversations with faculty advisors, and observations from site visits to each of the schools, the following recommendations and best practices should be considered when creating and designing future PAR projects.

**Provide More Student Training Sessions**

Many students, as well as faculty advisors, expressed the need for more training at the beginning of the project. Although positive feedback was reported from the initial training session, many felt that more than one day was required to efficiently carry out this type of project. Future projects should include multiple training sessions, where at least one session brings together the full group and additional sessions are held with each school individually.

Additionally, many students noted that they were nervous about presenting their findings to a large group as many had never presented in front of a group before. Future training should include public speaking and presenting guidance, particularly for students with communication challenges. It is also necessary to train all of the students on working with students with disabilities as many were unsure of how to proceed with team members who had communication difficulties.

**Provide More Training for Faculty Advisors**

Based on suggestions from faculty advisors, in addition to the initial training with all of the involved schools, it would be helpful to hold a similar training solely for faculty advisors so that they are able to ask questions and grasp the nature of the project before recruiting students. Most faculty advisors felt they needed more support to help students with data collection and analysis as this was not their area of expertise. Faculty only training on recruitment and research methods should be implemented in future projects.

**Improve Reference Resources**

In addition to more training, students requested more resources for understanding research methods. Although most students found the printed materials in the resource binder to be helpful, not all students learn most efficiently from written materials. Video tutorials that illustrate basic research methods should be included in future training materials.

Students requested more examples of ways to disseminate their findings. Although each of the teams came up with a creative way to share their results, many students had never created this type of product before and wanted more information on presenting statistics and the overall format of the report. Future iterations of the project should provide students with more examples of reports created for other PAR projects. Tutorials on creating charts and graphics in Microsoft Excel or any other program should also be included in future training.
Appendix A

Guidance on student recruitment provided to faculty advisors.
Strategies for Student Engagement

Introduction
The information in this guide has been adapted from a number of different resources on participatory action or inclusive research (PAR). Our hope is that this will serve as your guide as you progress through the various stages in the research project. We start with basic information about PAR, and try to provide a comprehensive range of additional information so that you are able to engage and support your students as efficiently as possible. Although this guide is not exhaustive of all of the information about PAR, it should serve as a quick reference as questions arise.

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Basic Information
• **What PAR?**
  o Participatory action research (PAR) is a collaborative process between researchers and the people who are expected to benefit from the research.

• **What is the purpose of PAR?**
  o PAR is intended to promote social change among vulnerable or marginalized groups, such as people with intellectual disabilities.
  o When members of a marginalized group take part in PAR, they are empowered to ask questions that they want answered, and to find solutions to problems based on their ideas and experiences.

• **How does PAR work for people with ID?**
  o PAR involves inclusive research approaches where people who would typically be seen as the subjects of research become full or partial participants in the research process. The goal of PAR is that the results from the research will help solve the real, “on-the-street” problems that stakeholders experience.

  o At a minimum, PAR involving people with ID should be guided by the following principles:
    ▪ The research question, problem, or issue must be one that is owned by people with intellectual disabilities.
    ▪ Participants communicate about important issues in need of exploring. This communication can be exploratory – open to explore all issues relevant to the group or topical – only open to explore issues related to set objectives.
    ▪ It should be collaborative. People with intellectual disabilities should be involved in the process of doing the research.
    ▪ This can be achieved through training people with ID to serve as co-researchers where they learn how to conduct focus groups, conduct interviews, and create reports.
    ▪ The research question, process, and reports must be accessible to people with ID.
    ▪ Reports should be created so that they are easy to read, use visual graphics rather than large blocks of text, are available in audio format, etc.
Role Descriptions
What will students do?

Overview
Project UNIFY of Special Olympics International (SOI) plans to team up with student leaders to test youth-led research methods that model the values of Special Olympics, including respect, dignity, and self-determination. This project will use participatory action research (PAR) methods to engage young people with and without intellectual disabilities as co-researchers. We are interested in understanding what it means to students with intellectual disabilities to feel included in their schools and communities. Students will partner with researchers on the following activities: creating research questions; creating data collection tools; collecting information; interpreting data; presenting findings; and making recommendations for changes in schools and communities.

Student Investigators
Student Investigators will be involved in all of the stages in the project. There will be 6-8 Student Investigators at each school.

Duties

<table>
<thead>
<tr>
<th>Think of research questions</th>
<th>Design surveys and tools</th>
</tr>
</thead>
<tbody>
<tr>
<td>![Smiley Face]</td>
<td>![Survey Design]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ask people to take surveys</th>
<th>Analyze data</th>
</tr>
</thead>
<tbody>
<tr>
<td>![Survey Question]</td>
<td>![Bar Graph]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Create reports</th>
<th>Tell other people about the research</th>
</tr>
</thead>
<tbody>
<tr>
<td>![Report Symbol]</td>
<td>![Speech Bubble]</td>
</tr>
</tbody>
</table>

Qualifications
Student Investigators should have the following qualifications:

- Participate in Project UNIFY
- Commitment to creating change at your school through inclusion and acceptance of all students
- Interest in helping with one more of the activities listed above
What will faculty supporters do?

Overview
Project UNIFY of Special Olympics International (SOI) plans to team up with student leaders to test youth-led research methods that model the values of Special Olympics, including respect, dignity, and self-determination. This project will use participatory action research (PAR) methods to engage young people with and without intellectual disabilities as co-researchers. We are interested in understanding what it means to students with intellectual disabilities to feel included in their schools and communities. Students will partner with researchers on the following activities: creating research questions; creating data collection tools; collecting information; interpreting data; presenting findings; and making recommendations for changes in schools and communities.

Faculty Supporters
One Faculty Supporter will be identified at each school and will serve as an advisor to students as they investigate their research questions.

Duties

<table>
<thead>
<tr>
<th>Attend training sessions with students</th>
<th>Help Student Investigators contact Project Facilitators when they have questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regular communication with Student Investigators to ensure the project is running smoothly</td>
<td>Ease communication between Student Investigators and Project Facilitators</td>
</tr>
<tr>
<td>Participate in bi-monthly meetings with Project Facilitators</td>
<td></td>
</tr>
</tbody>
</table>

Qualifications
Faculty Supports should have the following qualifications and/or interests:
- An established rapport with students involved in Project UNIFY
- Experience and/or interest in conducting research
- Ability to empower students to take full control of all project related decisions and tasks
What will Special Olympics do?

Overview
Project UNIFY of Special Olympics International (SOI) plans to team up with student leaders to test youth-led research methods that model the values of Special Olympics, including respect, dignity, and self-determination. This project will use participatory action research (PAR) methods to engage young people with and without intellectual disabilities as co-researchers. We are interested in understanding what it means to students with intellectual disabilities to feel included in their schools and communities. Students will partner with researchers on the following activities: creating research questions; creating data collection tools; collecting information; interpreting data; presenting findings; and making recommendations for changes in schools and communities.

Project Facilitators
Project Facilitators will work with Student Investigators and Faculty Supporters to ensure that all aspects of the research process are understood and questions are addressed as they arise. Project Facilitators are trained research staff from Special Olympics International in Washington, DC and The University of Ulster in Northern Ireland.

Duties

| Conduct bi-monthly meetings with Faculty Supporters | Teach students about research methods |
| Help Student Investigators with the technical parts of the research |
| Research Questions | Design Surveys | Create Reports | Analyze Data |
Information for Students
• **Why should I get involved in this project?**
  
  - Research gives answers to questions and helps us solve problems.

• **What will happen if I decide to participate?**
  
  - If you decide to be a part of the project, you will help create a research study with other Project UNIFY students to look at a problem in your school that is important to you.

  - Someone from Special Olympics International will explain the types of things you will be doing.

  - Then you decide if you want to participate.

  YES or NO
Information for Faculty Supporters
Tips for Recruitment

- The essence of PAR is to create a collaborative process where those who are typically the subjects of research have an active voice throughout the research process.

- A key strategy for engaging students to participate in this project is to facilitate student-to-student recruitment.

- As a faculty advisor, it is important to identify 2-3 student leaders who can work as a team to talk about the project with other students.

- Characteristics to look for in potential student leaders:
  - Active involvement in Project UNIFY
  - Strong interest in social justice and self-advocacy
    - the nature of this project requires students to delve into an issue that is important to them
  - Willingness to talk to other students on campus and recruit students to participate
  - Demonstrated leadership skills both in the classroom and in extracurricular activities

- Ideally, a strong student leader will be able to motivate and communicate well with his or her peers. Student leaders should be able to excite other students about getting involved and addressing an issue of importance.
## Project Timeline

<table>
<thead>
<tr>
<th>ACTION ITEM</th>
<th>PERSON/ORGANIZATION RESPONSIBLE</th>
<th>TARGET DATE</th>
<th>COMPLETION DATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Submit IRB application for Phase 1 (planning and recruitment).</td>
<td>Janelle Nanavati/SOI</td>
<td>July 2012</td>
<td></td>
</tr>
<tr>
<td>3. Recruit faculty supporters from four participating school sites.</td>
<td>SOMD</td>
<td>July 2012</td>
<td></td>
</tr>
<tr>
<td>4. Recruit student leaders with ID from each of the participating school sites.</td>
<td>SOMD</td>
<td>July 2012</td>
<td></td>
</tr>
<tr>
<td>5. Recruit Project Steering Committee members.</td>
<td>SOI, SOMD</td>
<td>July 2012</td>
<td></td>
</tr>
<tr>
<td>6. Convene Steering Committee in person or by phone.</td>
<td>Janelle Nanavati/SOI</td>
<td>August 2012</td>
<td></td>
</tr>
<tr>
<td>7. Create materials for student recruitment.</td>
<td>Rachel Moscato/SOI</td>
<td>August 2012</td>
<td></td>
</tr>
<tr>
<td>8. Establish social networking platform.</td>
<td>Rachel Moscato/SOI</td>
<td>August 2012</td>
<td></td>
</tr>
<tr>
<td>9. Recruit students and enroll in study.</td>
<td>Student Investigators, Faculty Supporters</td>
<td>August 2012</td>
<td></td>
</tr>
<tr>
<td>10. Facilitate training with student investigators, faculty supporters, SOMD, and SOI.</td>
<td>Roy McConkey, Janelle Nanavati/SOI</td>
<td>October 2012</td>
<td></td>
</tr>
<tr>
<td>11. Determine student research project questions and data collection strategies.</td>
<td>Student Investigators (with support)</td>
<td>October 2012</td>
<td></td>
</tr>
<tr>
<td>12. Submit IRB application for Phase 2 (student projects implementation).</td>
<td>Janelle Nanavati/SOI</td>
<td>October 2012</td>
<td></td>
</tr>
<tr>
<td>13. Convene Steering Committee meetings.</td>
<td>SOI, SOMD</td>
<td>Quarterly</td>
<td></td>
</tr>
<tr>
<td>15. Analyze data.</td>
<td>Student Investigators, SOI</td>
<td>March 2012</td>
<td></td>
</tr>
<tr>
<td>16. Create final report/work product that explains project findings.</td>
<td>Student Investigators</td>
<td>May 2012</td>
<td></td>
</tr>
<tr>
<td>18. Disseminate findings to relevant stakeholder groups.</td>
<td>Student Investigators, Janelle Nanavati/SOI</td>
<td>July-August 2013</td>
<td></td>
</tr>
</tbody>
</table>
Additional Resources
Inclusive Research Groups

There are a number of universities, organizations, and independent research groups utilizing participatory methods for research projects. A few prominent groups are listed below.

- **The Inclusive Research Network** - This network is run by volunteers who are, or who have been, involved with inclusive research including people with intellectual disabilities. They group is based in Ireland and conducts research projects in collaboration with Trinity College in Dublin. [http://www.tcd.ie/niid/research/irn/](http://www.tcd.ie/niid/research/irn/)

- An example of their work called “Where we Live” is included in this guide and can serve as an example of how the Project UNIFY study will work.
Appendix B
Resource binder provided to students and faculty advisors.
Project UNIFY

Youth-Led Research Project

If you have any questions or concerns contact:

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Introduction

Welcome to the Project UNIFY Youth–Led Research Project! We are happy you have joined your school’s research team, and we believe we will all learn a lot from each other as we get to work. We will be here to support you throughout your project, but you are the real experts and leaders in this initiative. This binder contains some basic materials to get you started. We will provide you additional resources when we meet with you at your school, and you can ask us questions anytime!

“One of the most difficult problems we face is to make it possible for young people to participate in the great tasks of their time.”

~ John W. Gardner, Self Renewal
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Basic Information
• **What inclusive research?**
  o Inclusive research is research where students of all ability levels are included in creating and working on the project.

• **What is the purpose of inclusive research?**
  o Inclusive research is meant to promote social change about an issue that is important to students at your school.
  o When students of all ability levels come together to do inclusive research, they work together to ask questions that they want answered, and to find solutions to problems based on their ideas and experiences.

• **How does inclusive research work?**
  o Inclusive research works when people who would typically be seen as the subjects of research become full or partial participants in the research process. The goal of inclusive research is that the results from the research will help solve the real, “on-the-street” problems that students experience.

  o Inclusive research should be guided by the following principles:
    ▪ The research question, problem, or issue must be one that is owned by students.
    ▪ Participants communicate about important issues in need of exploring.
    ▪ It should be collaborative. Students of all ability levels should be involved in the process of doing the research.
    ▪ This can be achieved through training students of all ability levels to serve as co-researchers, where they learn how to conduct focus groups, conduct interviews, and create reports. Everyone has something of valuable to contribute to the process.
    ▪ Reports should be created so that they are easy to read, use visual graphics rather than large blocks of text, are available in audio format, etc.
Role Descriptions
What will students do?

Overview

Project UNIFY of Special Olympics International (SOI) plans to team up with student leaders to test youth-led research methods that model the values of Special Olympics, including respect, dignity, and self-determination. This project will use inclusive research methods to engage young people of all ability levels as co-researchers. Students will work together to accomplish the following: create research questions; create data collection tools; collect data; interpret data; present findings; and make recommendations for changes in schools and communities.

Student Investigators

Student Investigators will be involved in all of the stages in the project. There will be 6-8 Student Investigators at each school.

Duties

<table>
<thead>
<tr>
<th>Think of research questions</th>
<th>Design surveys and tools</th>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Ask people to answer questions</th>
<th>Analyze data</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Create reports about what we learned</th>
<th>Tell other people about the research</th>
</tr>
</thead>
</table>

Qualifications

Student Investigators should have the following qualifications:

- Participate in Project UNIFY
• Commitment to creating change at your school through inclusion and acceptance of all students
• Interest in helping with one more of the activities listed above

What will faculty supporters do?

One Faculty Supporter will be identified at each school and will serve as an advisor to students as they investigate their research questions. The faculty supporters are there to provide support to students, not to run the project or do all the work.

Duties

<table>
<thead>
<tr>
<th>Attend training sessions with students</th>
<th>Help Student Investigators contact Project Facilitators when they have questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regular communication with Student Investigators to ensure the project is running smoothly</td>
<td>Ease communication between Student Investigators and Project Facilitators</td>
</tr>
</tbody>
</table>

Qualifications

Faculty Supports should have the following qualifications and/or interests:
• An established rapport with students involved in Project UNIFY
• Experience and/or interest in conducting research
• Ability to empower students to take full control of all project related decisions and tasks
What will Special Olympics do

**Project Facilitators**
Staff from Special Olympics will work with Student Investigators and Faculty Supporters to ensure that all aspects of the research process are understood and questions are addressed as they arise. Project Facilitators are trained research staff from Special Olympics International in Washington, DC and The University of Ulster in Northern Ireland.

**Duties**

<table>
<thead>
<tr>
<th>Conduct bi-monthly meetings with Faculty Supporters</th>
<th>Teach students about research methods</th>
</tr>
</thead>
</table>

Help Student Investigators with the technical parts of the research

- Research Questions
- Design Surveys
- Create Reports
- Analyze Data
The Basics
What’s in it for me?

- **Why should I get involved in this project?**
  - Research gives answers to questions and helps us solve social problems.

- **What will happen if I decide to participate?**
  - If you decide to be a part of the project, you will help create a research study with other Project UNIFY students to look at a problem in your school that is important to you.
  - Someone from Special Olympics International will explain the types of things you will be doing.
  - Then you decide if you want to participate.

**YES or NO**
Why would I want to be part of this?

- Inclusive research is an awesome way for you to talk about issues that are important in your school.

- It will help you learn to engage with your fellow students to advocate for issues important to you.

- The results from your research can be used to talk to school administrators and policymakers about issues that students care about.

- You can share your results with other students and come up with solutions for these issues.

- You will learn how to create reports and share your work with a large audience.

- You will be able to create a portfolio of your work on this project to demonstrate your new research skills to employers and college admissions teams.
How to do Inclusive Research
Where do research questions come from?

Deciding what to research is the first step in the research process. Brainstorming with your team will help you figure out what you want to study.

These steps will help your team brainstorm ideas:

1. Identify problems at your school that you care about.
   - For example: bullying, social media, participating in clubs.

2. Rate the problems you come up with based on:
   - Importance of the issue – the “so what?” test.
   - Interest in the issue among your team members
     - What is the motivation on your team to explore this issue?
     - Is this issue important to other students and teachers?
   - How easy it will be to get answers about the issue
     - Does the issue focus on something that is happening in your school?
     - Will you be able to collect enough information about this issue within the timeframe you have?
     - (Hint: if you answered YES to both of these questions, you are on the right track!)

3. Turn your problem into a question:
   - For example: your team identifies bullying as an important issue at your school. Your research question could be: “What is the impact of bullying on students with disabilities at Super Cool High School?”
How will we collect the data?

Once your team has decided what research question you want to explore, the next step is to collect your data.

There are all kinds of ways you can collect data from people at your school. Here are some examples:

**Surveys!**

- A survey is a way to collect information from people about their knowledge, attitudes, and behaviors. For example:
  - Your teacher gives your class a survey to see how much you know about geography (collecting information about your knowledge)
  - Your Principal gives students a survey to find out how you feel about bullying in the school (knowledge about your attitudes)
  - Your coach gives your team a survey about how much you exercise (collecting information about your behaviors)

- Surveys help us get information from a large group of people very efficiently. For example:
  - You could ask an entire English class to complete a survey at one time.

- You can conduct a survey in many different ways. For example, surveys can be conducted:
  - Face-to-face
  - On paper, in person
  - On paper, through the mail
  - Online
  - Over the phone
Interviews!

- Interviews with people give you more control over answers and can be personalized for each person that you interview.

- Interviews give the person who is being interviewed a chance to ask questions if they do not understand something.

- It is important to be aware that people may feel uncomfortable answering some questions face to face, or they might give answers that they think you want to hear (this is called social desirability).

Focus Groups!

- A focus group is a meeting of a group of people to discuss topics related to your research question.

- Focus groups can help you uncover attitudes and opinions on your research topic.

- Focus groups usually have about 8-10 people who all have a similar background, and a researcher to lead the discussion. For example, a school Principal holds a focus group of 10 students from a Unified Bocce team to discuss sports goals in their school.

- When conducting a focus group, it is important to have someone take notes or record the session so that you do not miss any important information.
How do we analyze the data?

Data analysis is an important step in the research process that can make students nervous. When you get to this step, the staff from Special Olympics will work closely with you to analyze the results of your study. As students who know the issues you are studying best, you bring an important perspective to data analysis and ideas that might not otherwise have been considered. The type of analysis you do depends on the kind of data you collect. Our staff will work with you to create the best data analysis plan based on your research question and data collected.
There are two types of data you will collect and analyze during your project. You might collect only one type, or you might collect both.

<table>
<thead>
<tr>
<th>Qualitative Data</th>
<th>Quantitative Data</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overview:</strong></td>
<td><strong>Overview:</strong></td>
</tr>
<tr>
<td>• Deals with descriptions.</td>
<td>• Deals with numbers.</td>
</tr>
<tr>
<td>• Data can be observed but not measured.</td>
<td>• Data which can be measured.</td>
</tr>
<tr>
<td>• Colors, textures, smells, tastes, appearance, beauty, etc.</td>
<td>• Length, height, area, volume, weight, speed, time, temperature, humidity, sound levels, cost, members, ages, etc.</td>
</tr>
<tr>
<td><strong>Qualitative → Quality</strong></td>
<td><strong>Quantitative → Quantity</strong></td>
</tr>
</tbody>
</table>

**Example 2:**

- **Latte**
  - Qualitative data:
    - robust aroma
    - frothy appearance
    - strong taste
    - burgundy cup
  - Quantitative data:
    - 12 ounces of latte
    - serving temperature 150º F.
    - serving cup 7 inches in height
    - cost $4.95

**Example 3:**

- **Freshman Class**
  - Qualitative data:
    - friendly demeanors
    - civic minded
    - environmentalists
    - positive school spirit
  - Quantitative data:
    - 672 students
    - 394 girls, 278 boys
    - 68% on honor roll
    - 145 students with IEPs
Step 4: Sharing the Results

How do we share the data with others?

Once you have collected and analyzed your data, you will want to share your results with others. There are many different ways you can present your results, but no matter what method you choose, you should include the following information:

1. Explain why the issue you selected is important and what is already known about it, if anything.

2. Describe what you did in this project and why you do it.
   a. Explain the process of deciding on a problem and research question and analyzing your data.

3. Explain who was involved in the project
   a. Describe the roles of each person on your team
   b. Describe the role of your faculty supporter

4. Explain what you learned
   a. What are your results?
   b. What did your team learn from the results?
   c. What did your team learn about doing this type of project?

5. Share recommendations for action based on what you learned. How can your school or community improve based on what you learned?
This table gives you some suggestions for how you can present your results.

<table>
<thead>
<tr>
<th>Product</th>
<th>Purpose</th>
<th>Format</th>
<th>Target Audience</th>
</tr>
</thead>
<tbody>
<tr>
<td>Presentation</td>
<td>To summarize key findings.</td>
<td>Power Point</td>
<td>Students, Administrators, Teachers</td>
</tr>
<tr>
<td>Facebook Page</td>
<td>To communicate findings and provide forums for questions and answers.</td>
<td>Web</td>
<td>Students, Peers outside of your school</td>
</tr>
<tr>
<td>Brochure</td>
<td>To share results with school administrators or students.</td>
<td>Print/Web</td>
<td>Students, Administrators, Teachers</td>
</tr>
<tr>
<td>Photo Report</td>
<td>To show how you did your project and share the results using photos.</td>
<td>Poster Video Webpage</td>
<td>Students, Administrators, Teachers</td>
</tr>
<tr>
<td>Written Report</td>
<td>To summarize findings and explain your project.</td>
<td>Print</td>
<td>Students, Administrators, Teachers</td>
</tr>
</tbody>
</table>
Research Ethics
## Fundamental Principles of Research Ethics

<table>
<thead>
<tr>
<th>Principle</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td><strong>Respect for persons</strong></td>
<td>Respect for persons entails respecting the dignity of research participants. We should always keep what people tell us in research studies private by not ever sharing names with any data we collect.</td>
</tr>
<tr>
<td><strong>Beneficence</strong></td>
<td>People need to be told what is involved in the research project and understand risks if there are any. If they want to quit the project for any reason, that is their choice.</td>
</tr>
<tr>
<td><strong>Justice</strong></td>
<td>We should make sure we share what we learned with the people we collected data from. We should not learn new and important things and keep them to ourselves.</td>
</tr>
<tr>
<td><strong>Respect for Communities</strong></td>
<td>Respect for communities means that researchers must respect the values of the community involved in the research and protect the community from harm. This is very important in research which requires community-wide knowledge, values, and relationships and, thus, the community may be impacted by the research process or its outcomes.</td>
</tr>
</tbody>
</table>

Timeline
## Project Timeline

<table>
<thead>
<tr>
<th>ACTION ITEM</th>
<th>PERSON RESPONSIBLE</th>
<th>START DATE</th>
<th>COMPLETION DATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Recruit students for research teams and begin thinking of research</td>
<td>Student Investigators, Faculty Supporters</td>
<td>September 2012</td>
<td>December 7, 2012</td>
</tr>
<tr>
<td>questions.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Kickoff training with student investigators, faculty supporters, and</td>
<td>Janelle Nanavati, Rachel Moscato</td>
<td>December 7, 2012</td>
<td>December 7, 2012</td>
</tr>
<tr>
<td>Special Olympics staff.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Analyze data.</td>
<td>Student Investigators (with support)</td>
<td>March 1, 2013</td>
<td>April 1, 2013</td>
</tr>
<tr>
<td>6. Create final report/work product that explains project findings.</td>
<td>Student Investigators (with support)</td>
<td>April 1, 2013</td>
<td>May 1, 2013</td>
</tr>
<tr>
<td>7. Share findings with your school and other students.</td>
<td>Student Investigators, Faculty Supporters</td>
<td>May 1, 2013</td>
<td>May 31, 2013</td>
</tr>
</tbody>
</table>
Additional Resources
Inclusive Research Groups

There are a lot of universities, organizations, and independent research groups that use participatory methods for research projects. A few of the groups are listed below.

- **The Inclusive Research Network** - This network is run by volunteers who are, or who have been, involved with inclusive research including people with intellectual disabilities. They group is based in Ireland and conducts research projects in collaboration with Trinity College in Dublin. [http://www.tcd.ie/niid/research/irn/](http://www.tcd.ie/niid/research/irn/)

- An example of their work called “Where we Live” is included in this guide and can serve as an example of how the Project UNIFY study will work. **Included in this guide!**

Presentation Ideas

- **Photovoice** is a great way to share your results using pictures and videos. [http://www.photovoice.org/](http://www.photovoice.org/)
- **Many Eyes** is a free website where you can make charts and graphics to show your data. [http://www-958.ibm.com/software/data/cognos/manyeyes/](http://www-958.ibm.com/software/data/cognos/manyeyes/)
House by Shane Lonergan
from Moorehaven Centre in Tipperary Town

Where we Live
A National Study done by
Members of the Inclusive Research Network
ACKNOWLEDGEMENTS

Many people have worked on this project:

- People with intellectual disabilities who participated in the surveys.
- Ray Murray, Zoe Hughes, and Errol Cocks, research staff at the National Institute for Intellectual Disability, who participated in the Galway workshop.
- Mary Barrett, administration staff at the National Federation of Voluntary Bodies who supported members of the Inclusive Research Network, helped in the organisation of meetings and made contact with members of the Inclusive Research Network to write this report.
- Sarah Jones, research administrator at the National Institute for Intellectual Disability also helped following up with co-researchers and supporters when they did the survey and helped in the reviewing of this report.
- Co-researchers and supporters that did not do the surveys but have attended the workshops and shared their knowledge and ideas.
- Organisations and staff that supported co-researchers to survey people getting services from them.
- Everyone who kindly reviewed this report and made comments to make it easier to read.

We would like to thank them all for their effort in making this research project and report possible.
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</table>
The Inclusive Research Network is a group of people with intellectual disabilities from Ireland who do research.

We are supported by the National Federation of Voluntary Bodies and the National Institute for Intellectual Disability.

We organised 3 research workshops between 2008 and 2009 where we learnt research skills. We came up with the idea of doing a research project on: where people with intellectual disabilities live and how they like it.

We decided to do a survey to find out the answers. We did a survey with easy to read questions and pictures about where people live and how they like it. We practised how to ask the questions and how to write the answers.

11 members of the Inclusive Research Network did the survey with 43 people. These members did the survey from June to September of 2009. Staff at the National Institute for Intellectual Disability analysed the answers.

We then organised 2 meetings to discuss what we found out:

- Most people who did the survey were women and most people were between 20 and 35 years old.
- Most people liked where they lived.
• Most people lived in towns and with their families.

• Most people had their own kitchen, bedroom and bathroom.

• Most people had access to taxis and buses.

• More than half of the people did not choose who they live with and only half of the people chose where they live.

• Half of the people said that they would change things in their homes, only a few would change things about the people they live with, and some would change things about the support they get.

Members of the Inclusive Research Network said that more work needs to be done for them to live independently including: more services for people with intellectual disabilities, more control for people over funding, more choices about where and who to live with, more individualised supports, change in families’ attitudes about living independently and more opportunities for people with intellectual disabilities to be heard.
TEAM

The Co-Researchers

Simon Buggy  Carmel Carpenter  Nicole Carroll  Brian Donohoe  Sarah Flynn

Michael Freiberg  Ann Mahon  Emma McCormack  Seamus Murphy  Patricia O’Dea

Pauline O’Meara  Marie Wolfe

The Facilitators

The National Federation of Voluntary Bodies

Edel Tierney  John Doyle  Stephen Curtis
The National Institute for Intellectual Disability

Patricia O’Brien

Edurne García Iriarte

Darren Chadwick

The Supporters

Geraldine Bane

Antonio Cebas

Lavinia Donoher

John Doyle

Josephine Flaherty

Edurne García Iriarte

Michelle Joyce

Kieran Keon

Dawn Lonergan

Pauline O’Meara

Also Geraldine McNamara, Ellis O’Connor, Aine Taylor & Sara Teal

External Advisor

Roy McConkey
The Inclusive Research Network is a group of people who come together to do research and talk about research that is important to people with intellectual disabilities.

- The Inclusive Research Network is a joint project of the National Federation of Voluntary Bodies and the National Institute for Intellectual Disability.

- The IRN members are:
  - Co-researchers: people with intellectual disabilities doing research;
  - Facilitators: trained researchers;
  - Supporters: people who support the co-researchers.

- This network is for anyone interested in this type of research. For example, people from services, self-advocacy groups, organisations, researchers and community groups.
THE RESEARCH WORKSHOPS

We conducted 3 research workshops between 2008 and 2009.

- We learnt:
  - Basic research knowledge and skills.
  - Research methods.
- We gained some hands-on research experience.
- We explored issues about:
  - Who can do research?
  - Why do we do research?
  - Ethics and consent.

During these workshops co-researchers said that they would be interested in researching:

- Choice about who to live with.
- Freedom to be independent.
- Moving into my own house and independent living.
- Privacy and my rights.
- Alternatives to group housing.
The Inclusive Research Network decided to do a study about where people with intellectual disabilities live. We wanted to look at:

- What people like and do not like.
- What supports do people need.
- What people would like to change about where they live.

We decided to do a survey. This was a way to use and transfer the skills learned in the inclusive research workshops.

Developing the Survey

We developed the survey in different steps.

Workshops 1 & 2:
- The co-researchers made suggestions about the survey questions.
After workshops 1 & 2:

- The facilitators developed potential questions and added pictures.
- The co-researchers tried out the questions in Dublin and Galway and gave feedback:
  - Suggested new questions
  - Changed some of the questions:
    - The order to ask them.
    - The wording of questions.
    - The topics.

In workshop 3:

- We all sat in small groups of four and tried out the survey.
- The facilitators asked the co-researchers and supporters again to give feedback.

You can see the final version of the “Where We Live” national survey online at www.fedvol.ie.
Ethics

The project received ethical approval through the Research Ethics Committee at Trinity College Dublin.

The Survey Tools

We developed the survey, the answer booklet, letters of information, consent forms, a checklist and instructions.

Survey

Answer booklet

Letters of information
- For survey participants
- For supporters, organisations, and families

Consent forms
- For survey participants
- For supporters
All documents included pictures. We also checked the documents to make sure they were easy to read.

- We used pictures and questions from the “Adults with Learning Difficulties in England” 2003/4 survey with the permission of the authors.

- Other pictures used in the Where We Live survey or in this report were taken from © Photosymbols or taken at the IRN workshops with members’ permission.
How did We Survey People?

We did a training workshop in June of 2009 in Galway.

- All co-researchers had a chance to practice with the survey.
- Co-researchers took turns at asking and answering questions.
- Co-researchers had a chance to experience doing the survey and responding to the survey.
- Co-researchers also learnt about sampling different people to take part in the study:
  - Males and females.
  - People of different ages.
  - People who lived in different places (group homes, independent living, with family).
Following this meeting, some CO-RESEARCHERS volunteered to take part in the national study.

To take part in the national study, each co-researcher asked a family member, a staff person, or other people to be their SUPPORTERS to help them to do the survey.

Two FACILITATORS, one from the National Federation of Voluntary Bodies in Galway and one from the National Institute for Intellectual Disability in Dublin helped the co-researchers and supporters over the summer to keep deadlines and offered additional support.
The facilitators provided support to the co-researchers and supporters.

- The facilitators:

  - E-mailed co-researchers and supporters regularly.

  - Called some co-researchers and supporters who did not use e-mail.

  - Developed a website explaining how to do the survey and how to use all the materials.

  - Reminded the co-researchers and supporters to use the website.

  - Also worked as supporters.

- Most of the surveys were done between July and August, but we also allowed for late submissions.
11 Co-researchers did the survey.

- The co-researchers did the survey with people in their own area.

- The co-researchers were based in Galway, Clare, Monasterevin, Roscommon, Dublin, Waterford, Carrick-on-Suir and Cork.

- The role of the supporters was to:
  - Help co-researchers through all the steps.
  - Record the answers.
  - Make sure that each person who responded to the survey:
    - Understood what the study was about.
    - Signed a consent form.
The co-researchers and supporters sent the responses by post to the facilitators during August and September.

- The facilitators entered the data into a computer file and did statistical analysis.
- The facilitators presented the key findings to a group of co-researchers and supporters at a meeting.
  - The facilitators used a series of bar charts with pictures.
- Seven co-researchers and two supporters attended the meeting where everybody:
  - Discussed the findings.
  - Compared the findings from the study with co-researchers’ experiences of doing the survey.
  - The co-researchers discussed the key messages for the government and decision makers in organisations.
WHAT DID WE FIND OUT?

Co-researchers did 43 surveys around the country.

More than half of the people who responded were females and some were men.
Most people were aged between 20 and 35 years, or 36 and 50. Only a few were under 20 years or over 50 years.

Most people lived with their families, some lived in group homes, and a few in independent living apartments.
On average

- People who lived in group homes said that they lived with nine people.
- People who lived with their families said that they lived with three people.
- People who lived semi-independently, said that they lived alone or with one other person.
On average

- People who lived in group homes and people who lived with their families said that they had lived there for about 10 years.
- People who lived independently said that they have lived there for only about four years.

Most of the people said they had their own kitchen.
Most people said that they were able to use the kitchen when they wanted.

About half of the people said that they had their own bathroom.
Almost all people said that they had their own bedroom.

Only some people had a key to their bedroom.
Most people said that other people did not come into their bedroom when they were not there.

A lot of people lived in a town, many in the countryside and only a few in the city.
Most people had access to taxis and buses. Many had access to trains. Only a few had access to aeroplanes and trams.
In general, most people liked where they lived.

They said that they liked where they lived when:

- It was a nice house or flat.

  It is a nice and safe place.

  I like the garden, it's nice and big...
• It was near things that were important to them.

I am happy where I am because it’s my home, I know my neighbours, Granny lives beside me and the church is close. I like my family.

Because it is near work and town and a shop around the corner. Nobody giving out to me...

• They could be independent.

I like it because I can help around the house. I can walk to work, staff are nice to me.

Independent, come and go as I want...

• They liked the people they lived with.

Plenty of friends, happy with staff and house mate and area.

More space, see lots of nature; like the people I live with and mom and dad support me.
They said that they didn’t like where they lived when:

- There were no people around or no things to do.
  
  Because there are a lot of old people, there are no people of my own age. It's kind of boring.
  
  Too quiet, I have no friends there. There is not much to do or places to go.

- They wanted to have more independence.
  
  I love the countryside but want to move away from parents. I would like to live on my own independently. I want to be completely independent.

When we compared people living in group homes and people living with their families we found that:

- People living in group homes also liked where they lived because of the accessibility of their homes.
  
  Also good because all deaf signs.
More than half of the people did not choose who they live with.

Only half of the people chose where they lived.
About half of the people said that they would change things about their homes.

The things they would change about their homes were:

- Having their own homes and rooms.

A room of my own.

I would like to live in my own house.
• Choosing the people they lived with.

To move in with people and to be able to choose the people if possible.

• Changing room or house.

A bigger room and the colour. I'd like a new house. I would like to move, live with girls.

• Having more responsible landlords/landladies and more respectful neighbours.

Landlord should look after the house more. The neighbours are a problem and the landlady gives out sometimes and watches my every move.
• A few people wanted to do more around their home and have their houses kept better.

Get my telly working properly, better good, be mobile as much as I can, like less people.

It’s too quiet. I would like to do more things.
When we compared people living in group homes and people living with their families, we found that:

- People living in group homes said that sometimes they did not know the staff.

I like staff at the moment but sometimes relief staff come and I don’t know them.

- People living with their families wanted to have independence to do more things and have more trust from their parents to go out in the community.

I don’t want to be watched by my parents. I want more independence – to be allowed out more. I want more trust from my parents. I wish my parents were not afraid of others in the community hurting me.
Only a few said that they would change something about the people they live with.
They things they would change about the people they lived with were:

- Having more choice about who they live with and the independence they had.

I would like to be more independent but the people at home are so hard to please. I need staff around all the time to keep mom happy when I am going somewhere. I would like to live alone.

It might be nice down the line to get a house mate but it would only be good if I owned the house and could choose who I live with.
Some people said that they would change things about the support they get.

![Bar chart showing that 66% (27 people) said 'No', while 34% (14 people) said 'Yes'.]

They said they would change things about the support they got including:

- More support to go out.

I would like to be able to go out more in the evening with friends.

Support in going out and making friends - don’t get much support.
• Different people supporting them.

I'd like to see different people supporting me.

• More support to work.

Support with work in my community.

• More support to look after the house.

When I move I would like a small house with my friends. I would need help with looking after it.

• More independence.

Less support and to be more independent.
Was there anything else that people wanted to say about where they lived?

- Some people said they liked where they lived.

  Good relationship with parents and siblings... I love living on farm and with the animals. Freedom on the farm is great. I like not being forced to do things in a group like those in a group home. I was asked to join a group home and said ‘no I didn’t want to’. I would like to live in a house independently but not in a group home.

- Some people said they would like things changed where they lived.

  I'd like to be more safer. There are a lot of gangs, young people, drunk, very loud.
Some people said they lived independently.

Nice area, nice distance from town. Quiet enough because it’s a little bit out of the town. I have moved from family to semi independent housing where I lived with two people to move into my own county council house on my own.

This took 2 and half years. Showing the county council the problems with the semi independent housing it managed to speed up the process. The support person wrote a letter to the county council to say I had the ability to live independently. I got to furnish the house so I got to put the stamp on the place myself. I was supported by my family to do this and I am very happy that I got to do this myself and not have someone else doing this.
KEY MESSAGES FROM THE IRN MEMBERS

A group of co-researchers talked about what the findings meant to them. They concluded that:

- There is lack of services for individuals to seek independent living.
- More control over funding is needed for people to have choices about where they live and who they live with.
- Individual needs have to be considered and supports need to be in place so that it is less frightening for people to be independent.
- There are few choices for people to decide where they live and who they live with.
- Attitudes should change for families to allow their family member to be more independent.
• There are not enough opportunities for peoples’ voices to be heard.

CHALLENGES

We found some challenges while conducting this research.

• Ethical approval
Some organisations required the researchers to apply for ethical approval within each organisation.

• Support to work out of the organisation
Supporters and co-researchers found it difficult to get to do the survey after the workshop activities.
• **Contact with co-researchers**

It was difficult to keep in touch with some IRN co-researchers through emailing. Often communication depended on the support person getting the communication and passing it onto the co-researcher.

• **Making documents easy to read**

It was difficult to make easy to read documents for everyone. The co-researchers had different skills and the organisation of making accessible materials for everyone has many rounds of feedback.
• **Holiday time**

The co-researchers had difficulty finding support. We did the survey during the summer and many supporters were on holidays. Some organisations were also closed.

• **Co-researchers’ participation**

Most of the co-researchers were members of Advocacy services and it was difficult for co-researchers that were not in self-advocacy groups to do the survey.
Members of the Inclusive Research Network Simon Buggy, Sarah Flynn, and Marie Wolfe presented the findings of the “Where We Live” research project at the 2009 National Disability Authority Conference in Dublin. They were supported there by Pauline O’Meara and Michael Freiberg.
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Appendix C
Final products from each of the student research teams.

Walkersville High School:
The Role of Social Media at Walkersville High School.

Severna Park High School:
Diversity at Severna Park High School

Maurice J. McDonough High School:
How does stereotyping effect the school environment?
Appendix D
Consent form provided to each student investigator.
Special Olympics will collaborate with Project UNIFY students in your school to create a research project based on a social issue important to your school. This project is the first of its kind to take place in a high school setting, and is an excellent opportunity to have your voice heard on an issue that is important to you!

I understand that if I choose to participate in this project, I will commit myself to the items below from November 2012 until February 2013.

I agree to work with my team to complete the following tasks:

- Develop research questions
- Ask other students to participate in the project
- Help with data collection
- Analyze the data collected
- Create reports or other materials to present the research
- Do my part to tell others about the research

I understand that participating in this project will require the time-commitment outlined below:

- Participate in monthly team meetings to discuss the project and ensure that all aspects of the project are running smoothly
- At least one to two hours per week for recruitment, data collection, data analysis, and creating reports
- Attend training sessions and check-in meetings with Special Olympics staff

Participating in this project will also be beneficial to you. This project will strengthen your skills as you enter the workforce or college. By actively participating you will:

- Gain experience with the research process
- Learn how to create reports and share your work with a large audience
- Learn to engage with your fellow students to advocate for issues important to you
- Create a portfolio of your work on this project to demonstrate these skills to employers and college admissions teams

____________________________________  _____________________________________________
Student Signature/Date                    Faculty Advisor Signature/Date

____________________________________
Special Olympics Signature/Date